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ABSTRACT

"Family support" describes the philosophy of the Michigan Public Mental Health System. Family Support is also the name of a Michigan program that provides the supports that parents of children with developmental disabilities need to keep their families together. Services include respite care, client services management, parent and caregiver training, parent support groups, accommodative home improvements, sibling programs, adaptive equipment, and a family support subsidy. The Family Support Subsidy, which is 100% State funded, is a cash entitlement of approximately $3,000 annually provided to families with a taxable income below $60,000 per year who care for their children with severe impairments. Parents have flexibility to spend the subsidy in whatever way they wish to meet the special needs of their family. In evaluation activities, the majority of families reported spending the subsidy on clothing, education aides, general household expenses, sitters, medical expenses, and diapers. The subsidy is viewed by parents as a symbol of recognition by the State of the value of caregivers and the care they give. A copy of the program's Fiscal Year 1989 annual report to the Governor and Legislature is appended. This report describes the purpose of the subsidy, its effectiveness, its impact on families, outreach activities to identify new subsidy applicants, annual evaluation, and recommendations for improvements. (JDD)

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MICHIGAN'S FAMILY SUPPORT AND FAMILY SUBSIDY PROGRAMS

remarks for the

New Jersey Council of Executives - ARC

April 6, 1990

by

Susan Arneaud, Director, Michigan Family Support Services & Subsidy

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"Family Support" is a philosophy of the Michigan Public Mental Health System. Michigan is firmly committed to keeping families together. We believe that children with developmental disabilities - like all children - need loving family relationships. We believe in empowering families. We believe that families can best decide the services they and their children need. We believe that all out-of-home placements are temporary. We believe, absolutely, that children should not live in institutions.

Parents introduced this Family Support philosophy to the mental health system during a grass-roots effort to gain funding for one family support program in 1978. The pilot family support project funded in FY79 was expanded to four demonstration sites in FY80.

During the ten years since 1980, Family Support has become more than a philosophy. Family Support is now a state-wide program with a continuum of services developed to actualize the philosophy. The Family Support Program provides the supports that parents have identified as necessary to keep families together. The program is family-focused; family initiated; utilizes permanancy planning principles; and seeks to be accessible, flexible, and unobtrusive.

Most services are available to birth families, adoptive families, and legal

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guardians who care for their family member - of any age - with developmental disabilities at home. Services include: Respite care, in and out of home; Client Services management; Parent and Care-giver training; Parent Support Groups; Accommodative Home Improvements; Sibling Programs; Adaptive Equipment; the Family Support Subsidy and other services as needed.

The Family Support Subsidy, was enacted in 1983 - as a result of another grass-roots effort by families. The Subsidy meets all the criteria identified by families as necessary for a family support service. It is simple to apply for, allows families the flexibility to determine what is needed for their family, is not intrusive.

Before I describe the Family Subsidy in detail, I'd like to give you some understanding of the way mental health services are structured in Michigan. Services are delivered at the county level by Community Mental Health programs. There are 55 in the State. Policy, as well as the standards and guidelines of service delivery, are developed and monitored by the State Department. The county programs contract with the State Department for 90% state funding against a 10% county match. The Family Subsidy is 100% State funding.

Each county program has a Family Support and Family Subsidy Progam with a coordinator to run it. Each Family Support program also has a Parent Advisory Committee. The PAC's serve different functions in different counties - some PAC's more active than others - and most meet monthly. I meet with the Coordinators every two months. The group is called the Family Support Coordinators' Council. My office is also on the phone with them daily - trouble-shooting and answering questions.

The Family Subsidy Program. As I mentioned, the cash subsidy is one of the family supports that meets all the criteria that families requested. It is an entitlement to families who care for their children with severe impairments. Everyone who meets the eligibility requirements receives the Subsidy - there is no waiting list and it is very easy to apply for.

Eligibility requirements:

-The child must be younger than 18 years old. When a child turns 18, the child is eligible, in almost all cases, for SSI. The Subsidy amount is patterned after the amount of SSI an adult receives who lives in the home of another.

-The child must live at home with a parent or legal guardian. The family must live in Michigan. It is OK for the child to live temporarily with a relative. We wanted to be certain that children could visit their non-custodial parent, or their grandparents without penalty.

-The family must have a taxable income below $60,000 per year. Middle income and upper middle income families were very vocal to the legislature about their needs. Before the Subsidy, many families made too much money to get any help for their children with disabilities...but didn't make enough to meet the extra costs of their children's special needs. Middle income families were very upset that they could only get help for their children if they gave them up. Parents did not want any cap on income. $60,000 was a compromise with the Legislature who wanted a lower cap.

-The Subsidy uses the diagnostic categories that are determined by the public schools for the child's special education program. This was a result of strong feelings of families and the Legislature that there should be no

additional assessment of children - who were already over-assessed. Parents did not want to have to jump through one more hoop. The Legislature did not want to have to fund an unnecessary assessment. In looking for an assessment that was already in place, the school assessment seemed the best. It was already required by law and available to all. The diagnostic categories matched closely with the types of diagnoses that would allow a child to be admitted to a State institution. The intent was to identify those children whose disabilities were the most severe.

-Severely Mentally Impaired

-Severely Multiply Impaired

-Autistic Impaired (with a program designated for AI)

-The current amount of the Subsidy is $256.74. The yearly total per family is $3080.88 This is the FY88 SSI amount. We have not been able to increase the monthly Subsidy amount for the last two years. We have also not had to cut the amount. The appropriation for FY 90 is $11.2 million.

-The application process is streamlined and efficient. There is a one-page application form that must be submitted initially and each year during the child's birth month. Families do not have to be mental health clients - they do not even need to be seen in person if they would rather apply through the mail. The documents that accompany the form the first time are the child's birth certificate, something which identifies the child's social security number, the parents' tax return, and a memo or other verification from the school that the child has an eligible diagnostic category. Each year, the parents must get a new memo from the school and submit their most current income tax form. Parents who do not file income taxes can submit something that verifies their income.

-The Subsidy goes to families all over the state. This map shows the community mental health programs and the number of families receiving the Subsidy for each program. Currently we are serving approximately 3500 families.

-This chart shows the characteristics of all families who are receiving the subsidy. Although most of the children are older than 7, the majority of new applicants are younger than 6 years old.

-The representation of gender and race/ethnic groups are very close to the population-at-large.

-Although many middle-income families receive the Subsidy, the largest group has a taxable income lower than $20 thousand per year.

-Parents have flexibility to spend the Subsidy in whatever way they wish. Families have to verify, once per year on the application form, that they have spent and they will spend the Subsidy on the special needs of their family. We do ask parents on the annual optional and anonymous evaluation how they have used the subsidy.

-As you can see, a majority of all families reported spending the Subsidy on the first-listed 6 items - clothing, education aides, general household expenses, sitters, medical expenses, and diapers.
--There is a slightly different pattern of spending for families at different income levels. Lower income families reported general household expenses second to clothing, with education aides 3rd, and transportation 4th. The highest income families reported sitters 3rd right after education aides - with respite care, medical related expenses, and adaptive equipment coming

before household expenses and transportation.

On the same annual survey, we ask about services the families still need, services they have enough of and services they don't need. We were not surprised to see Sitters as the service most families need more of. Although 100% of the county programs have sitter service (some have trained sitters, some have a cooperative, many have a voucher system with Family Friends - most counties have all three plus residential respite) there is never enough to go around. We were, however, surprised to see Life Planning as the second most needed service. We started work on that one right away.

Michigan has found that the Subsidy together with the rest of the Family Support Program is very successful at meeting the purpose of the Family Subsidy Act. The purpose is to keep families together and to avert and delay out-of-home placements.

Since the Subsidy's inception in 1984, the number of children in institutions has been reduced from nearly 200 to fewer than 30. An independent evaluation of the Subsidy program found that there was a significant reduction in the number of mothers who were even anticipating placing their child away from home at some future point - after receiving the Subsidy for about a year.

There have been some additional unplanned benefits reported to us by parents.

-The Subsidy gives status to the child. The child's special needs are not the financial liability they were before the subsidy. The child's special needs are the reason that dollars are made available to the family. Families do not have to deprive their other children on behalf of the special needs of one.

-And, finally, the Subsidy is a symbol - it is seen by parents as an award of recognition by the State - of the value of caregivers and the care they give.

These unplanned benefits, alone, make the Subsidy successful.

FAMILY SUPPORT SUBSIDY PROGRAM

ANNUAL REPORT
TO THE GOVERNOR AND LEGISLATURE

State of Michigan
John Engler
Governor

Michigan Department
of Mental Health
James K. Haveman, Jr.
Director

FISCAL YEAR 1989

FAMILY SUPPORT SUBSIDY PROGRAM

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FAMILY SUPPORT SUBSIDY PROGRAM

THE PURPOSE OF THE SUBSIDY IS TO KEEP FAMILIES TOGETHER

I am very thankful that this program is offered to us. It helps a great deal in our lives. Bless you.

Berrien County Parent

Supporting families is a high priority of Michigan's public mental health system, as evidenced by such services as the Family Support Subsidy Program. Michigan's philosophy is that children with developmental disabilities, like all children, need loving and enduring family relationships. Michigan believes that all out-of-home placements for children are temporary. Michigan believes, absolutely, that children should not live in institutions.

The Family Support Subsidy Act, Public Act 249 of 1983, was the beginning of a major shift of Michigan's mental health resources and services toward supporting, maintaining and establishing permanent family relationships for children with severe disabilities. Many children who receive the subsidy cannot talk, walk, or feed and dress themselves. Often, they have both mental and physical impairments and require 24-hour care. As a result, the families of children with severe disabilities have many expenses that other families do not. The Family Support Subsidy recognizes that families have differing and unique needs.

The Subsidy, like other services which support families with children who have severe disabilities, is a winning program. It enables the family to stay together, allowing them the flexibility to purchase goods and services at a local level. Children who live with their families thrive within their home environment. Parents want their children at home. In addition, it is less expensive to taxpayers than residential care.

THE SUBSIDY SUCCESSFULLY MEETS THE PURPOSE

The Subsidy Reunited 34 Children with Severe Disabilities with Their Families During FY89.

The subsidy has benefitted many families throughout Michigan. Parenting a handicapped child is an awesome responsibility and the subsidy helps deal with the pressure and stress associated with that responsibility.

Kalamazoo County Parent

Thirty-four children were reunited with their families during FY89. Twenty-one of these children returned home for the first time since the subsidy's inception. Their families received the one-time double subsidy to prepare for the childrens' homecoming. Thirteen additional children went home to their families.

The Number of Children with Severe Disabilities in Institutions has been Reduced by 82% in the last 5 years from 175 in FY83 to Only 31 in FY89.

The Subsidy really helps meet expenses that I could not have imagined in caring for a handicapped child. In addition to prescription medication and equipment, there are many, many over the counter preparations and special devices that our child needs to be happy and comfortable. Our family is very grateful for the Family Support Subsidy. We hope that in the quake of state budgeting tug-of-war that the subsidy is supported and not reduced.

Bay-Arenac County Parent

The Subsidy continues to be instrumental in bringing children out of institutions. As Figure 1 shows, at the end of FY89, only 31 children under the age of 18 lived in a Center for Developmental Disabilities. At the inception of the Subsidy in 1983, 175 children younger than 18 were in centers for developmental disabilities. FY89 represents a total reduction of 144 or 82% in the past 5 years.

Only 14 Out of the 3,491 Subsidy Children Were Placed Out-of-Home During FY89.

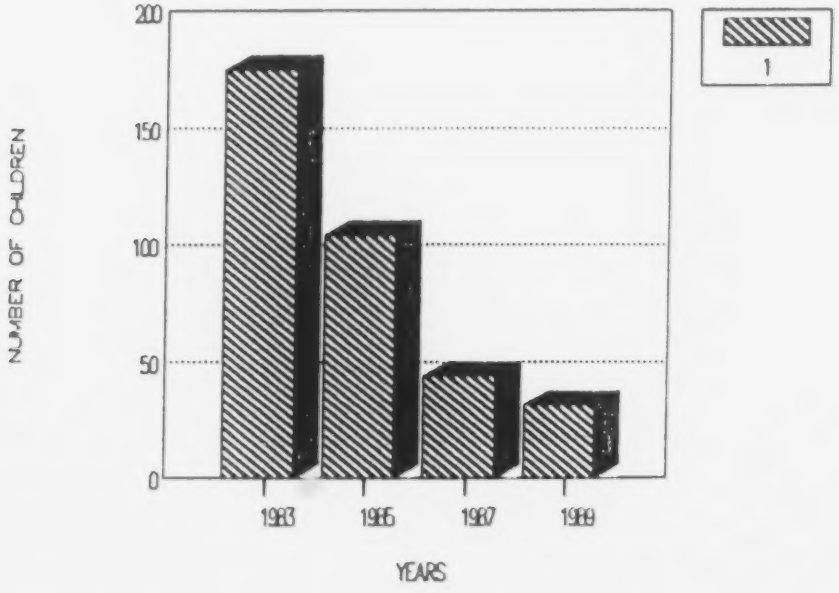
The family support subsidy program is a very good program. It has helped ease some of the financial and medical burden we have with a severely handicapped child. We love our daughter as much as our other two children, but the lack of sleep every night and daily stress is not easy at times. Programs like this one are great. Thank you.

Allegan County Parent

Only 14 Subsidy children placed out-of-home during FY89 were in out-of-home placements at the end of FY89. CMH boards reported a total of 42. Upon careful follow-up at year-end, however, it was discovered that five of the children had returned home. An additional three are eighteen and no longer eligible; one moved out of Michigan; five are older than 15 and are in adult placements; two have revolving eligibility (home on weekends, holidays and summers); one child died; four were counted as having been placed when there was not a placement; and a final seven are not clients of the mental health system. While follow-up was pursued with the families who are not clients, the children are not in mental health facilities and we have no authority to intrude further.

NUMBER OF CHILDREN UNDER EIGHTEEN

CENTER FOR DEVELOPMENTAL DISABILITIES



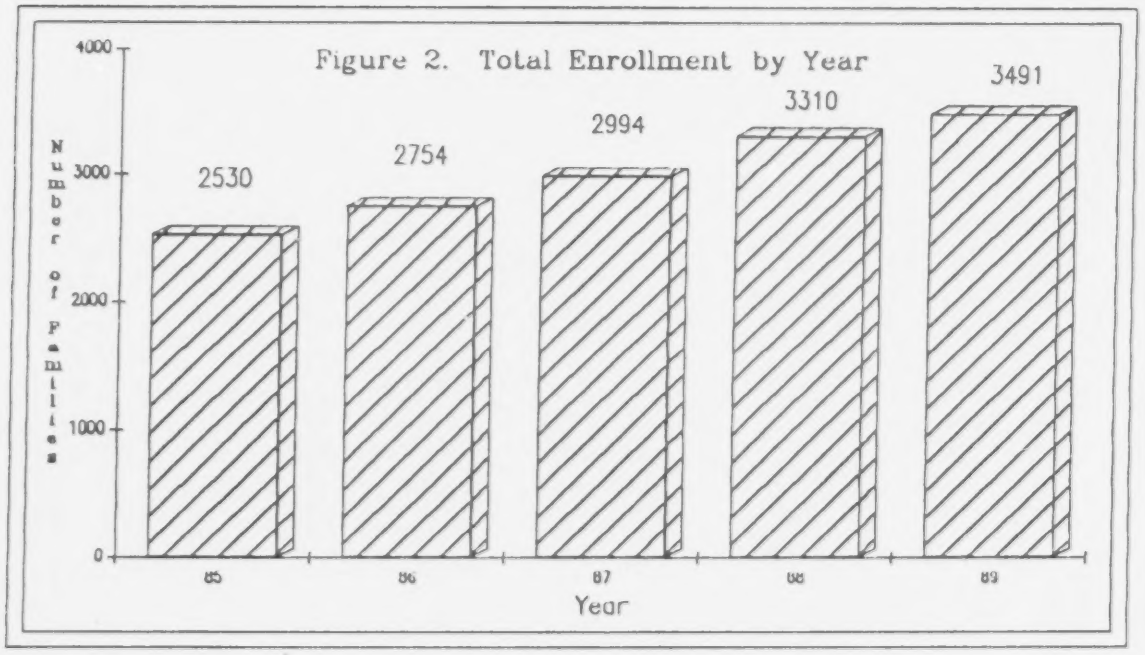
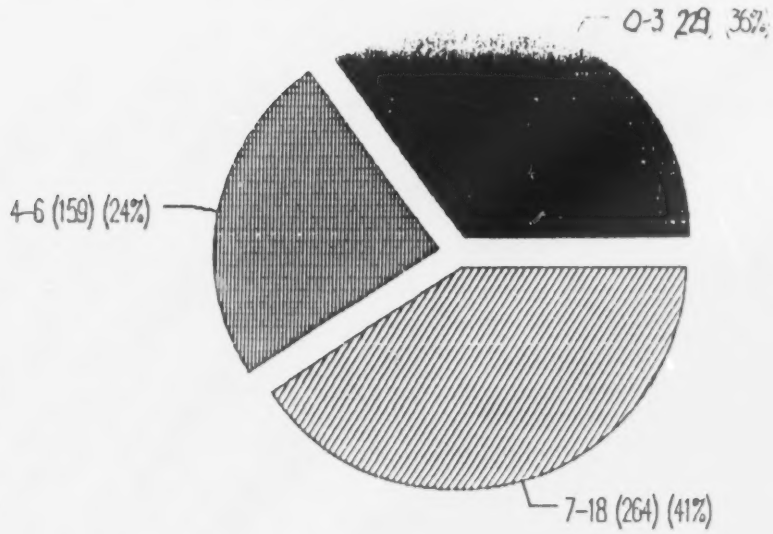
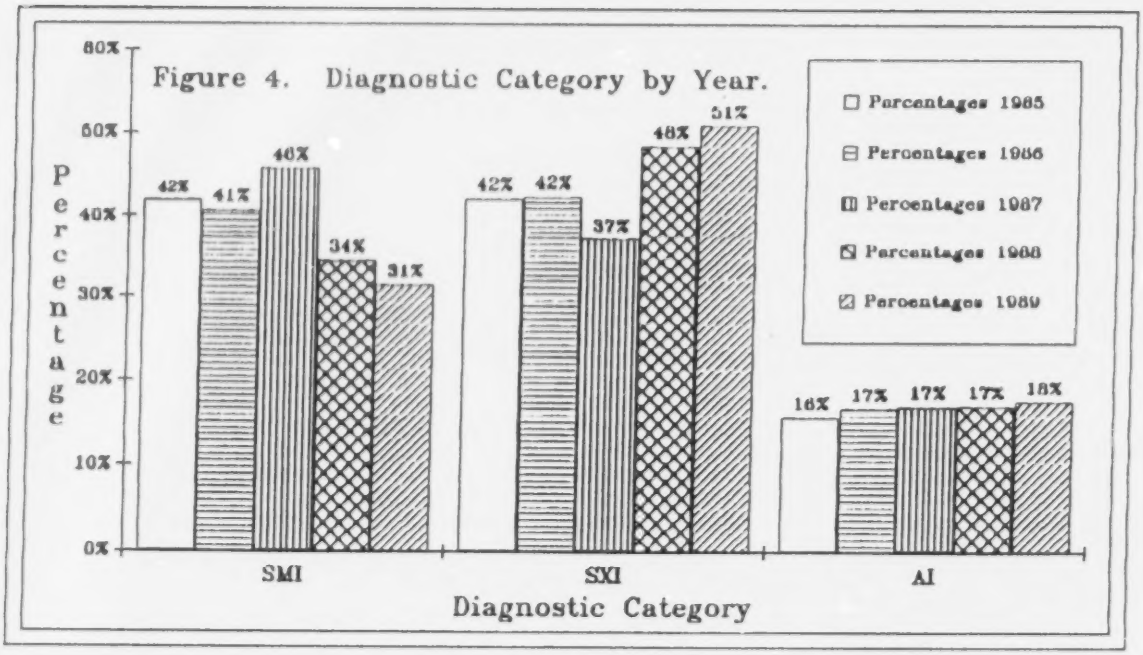


FIGURE 3

NUMBER OF NEW APPLICANTS BY AGE FISCAL YEAR 1989





THE PROGRAM

At the End of FY89, 3,491 Children With Severe Disabilities Were Receiving the Subsidy.

> *I think its wonderful -- I didn't think anybody knew what it was like to support a person who is impaired for life and that they may need a little help. It seems like its your way of showing that you know people with impairments do exist, and you have services to offer to help the parents and child make life easier. Thank you so much!! (Please keep the program going.)*
>
> *Oakland County Parent*

At the end of FY89, as of September 30, 1989, there were 3,491 families enrolled in the Subsidy Program. The FY89 subsidy expenditures for all families totalled $10.2 million. Figure 2 compares the total enrollment by year.

The Majority of the 652 New Subsidy Applicants Enrolled During FY89 Were Younger Than 6 Years Old.

> *Receiving the Family Support Subsidy helps us financially meet the needed expenses of therapy for our child. Without it, I feel he would not be as progressed as he is.*
>
> *Huron County Parent*

New applicants enrolled during FY89 numbered 652. Of the new applicants, 35% or 229 were 0 through 3 years old. As Figure 3 shows, 159 or 24% were ages 4 through 6. In all, 60% of FY89 applicants were children 6 years old or younger. Of the 652 applicants, 264 or 40% were ages 7 through 17.

Of all new applicants enrolled during FY89, 365 or 56% were diagnosed as Severely Multiply Impaired (SXI), 175 or 27% were Severely Mentally Impaired (SMI), and 112 or 17% were diagnosed as Autistic Impaired (AI). This distribution is fairly consistent with and follows the trend of the total group of Subsidy recipients.

Changes in the percentage of children in each diagnostic category are presented in Figure 4 for the 5 years the program has been in operation. The autistic impaired category has increased by one percent. In the last two years, the severely mentally impaired category has decreased by approximately the same percentage that the severely multiply impaired category has increased. We believe that this reflects the change in the rules governing the diagnostic categories rather than a change in the kinds of impairments children are experiencing. The definitions of the diagnostic categories were changed in the Special Education administrative rules when the rules were revised in July of 1987.

The Application Process is Streamlined and Efficient

> *Another strong point of the program is the absence of red tape in applying for the subsidy. Please don't change this! Families with handicapped children are under enough stress as it is and have neither the time nor the energy for yet another annual interview and form-filling session in addition to those they already encounter. We appreciate the help and thank you for an excellent program.*
>
> *Copper County Parent*

The application process was designed to be simple, accountable, and to make use of documents already available to families. Parents were asked about the ease of the application process. Table I shows that 90% reported that it was easy or very easy to get the required documents. The length of the application form is only one page. To complete the application, the one page form must be supported by: a copy of the child's birth certificate which verifies age; a copy of the family's Michigan income tax return to verify taxable income; and verification from the local school district of an eligible diagnostic category. The Subsidy uses the diagnostic category recommended by the school's Multi-disciplinary Evaluation Team (MET). The MET evaluation is necessary for Special Education services.

In addition, the child must have a Social Security number. The Subsidy is paid to the parent on behalf of the child in the child's social security number. The Subsidy is considered a benefit to the child. Subsidy income is not taxable.

Table 1
Ease of Application Process
Distribution of Responses

How difficult was it to get:	Very Difficult 1	Difficult 2	Somewhat Difficult 3	Easy 4	Very Easy 5
Your child's birth certificate	1.4%	1.0%	6.1%	51.1%	40.5%
Letter from school about your child's classification	.7%	1.1%	4.8%	48.8%	44.6%
Your Michigan tax form	1.3%	1.6%	4.7%	50.7%	41.8%
Your child's social security number	1.2%	1.1%	4.7%	50.4%	42.6%

Upon receipt of the completed application, the County Community Mental Health Board verifies the family's eligibility. Each year, the family is required to re-verify eligibility for the program in the birth month of their child. Coverage in the program begins the month following the month during which the completed application was received by the Community Mental Health Board.

The Subsidy Rules specify that Subsidy families are not clients of the Mental Health System unless they choose to become clients by requesting other services. This rule was in response to parents and advocacy groups who felt strongly that, while it was necessary for parents to be accountable, it was not necessary to have the limitations or the protections afforded to recipients of the Mental Health system.

Only Children with the Most Severe Impairments are Eligible

> *We are very glad to have it....Our daughter is totally fed through a gastrostomy tube....She is in a wheelchair, she is 8 years old functioning at a 9-24 month old level....She misses approximately 5 months of school a year due to illness. She has had 16 surgeries mostly all emergencies--shunt malfunctions; she has hydrocephalus, cerebral palsy, and is blind; she can't sit, walk, or talk.*
>
> *Monroe County Parent*

Families may be eligible for this program if they have a child under age 18 who has been recommended by a public school district's multidisciplinary team as:

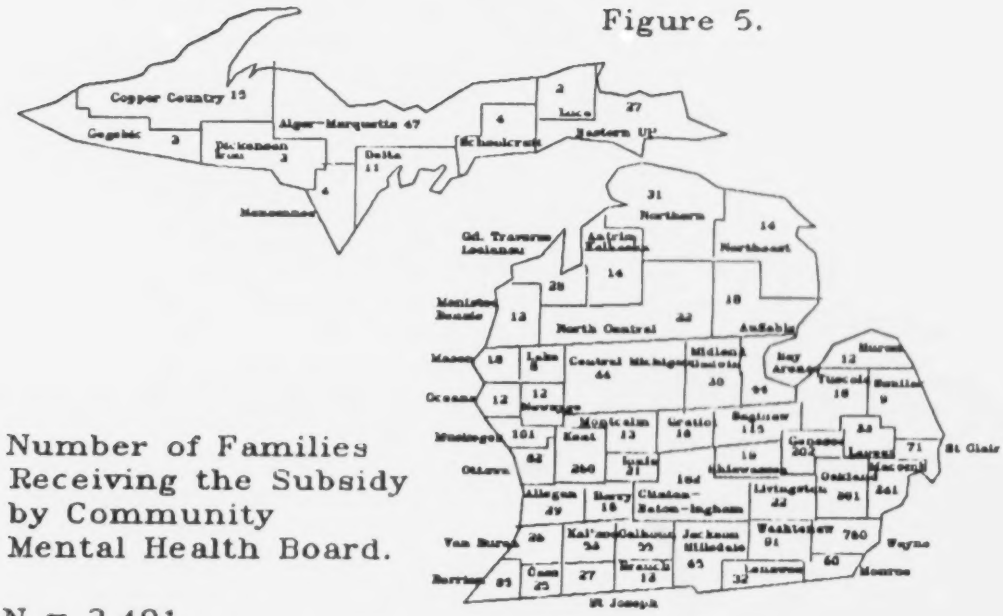
- severely mentally impaired (SMI)
- severely multiply impaired (SXI)
- autistic impaired (AI)

Children with autistic impairments must be enrolled in a classroom for severely mentally impaired; severely multiply impaired; autistic impaired; or be in a program for the autistic impaired that qualifies under the Act.

Families can be headed by natural parent(s), adoptive parent(s), or legal guardian(s). The child must be living in the home of the family and the family must reside in Michigan.

Under the law, the Michigan taxable income for the family may not exceed $60,000. In addition, the family cannot have an open medical subsidy case with the Adoption Subsidy Program administered by the Department of Social Services if they choose to apply for this program.

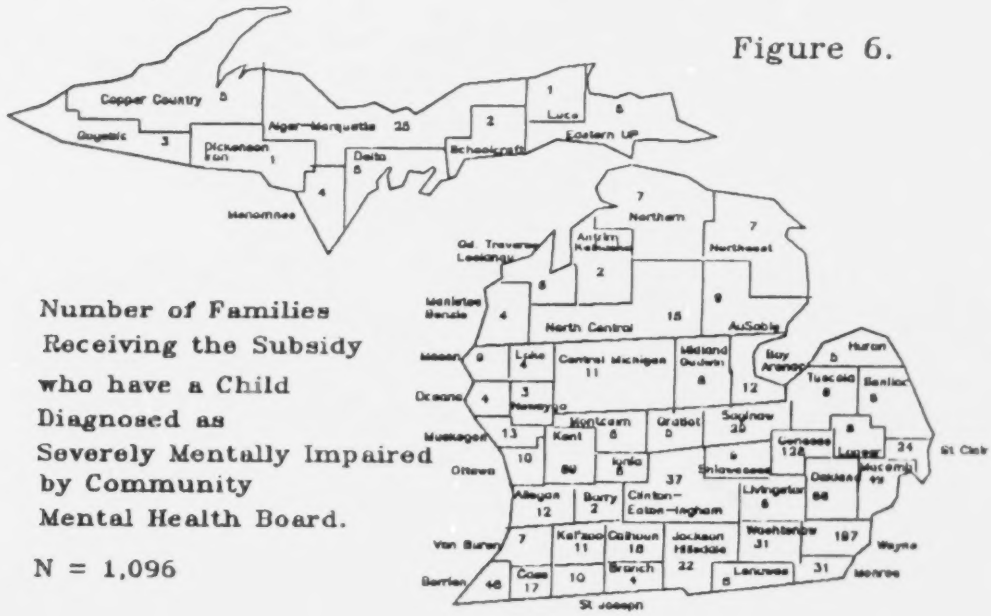
Figure 5.



Number of Families Receiving the Subsidy by Community Mental Health Board.

N = 3,491

Figure 6.



Number of Families Receiving the Subsidy who have a Child Diagnosed as Severely Mentally Impaired by Community Mental Health Board.

N = 1,096

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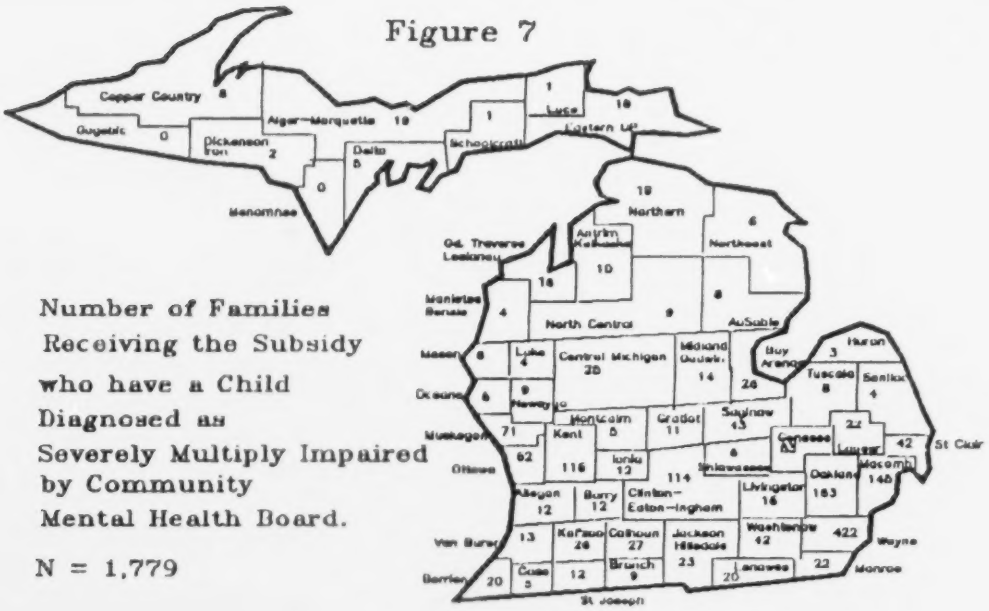
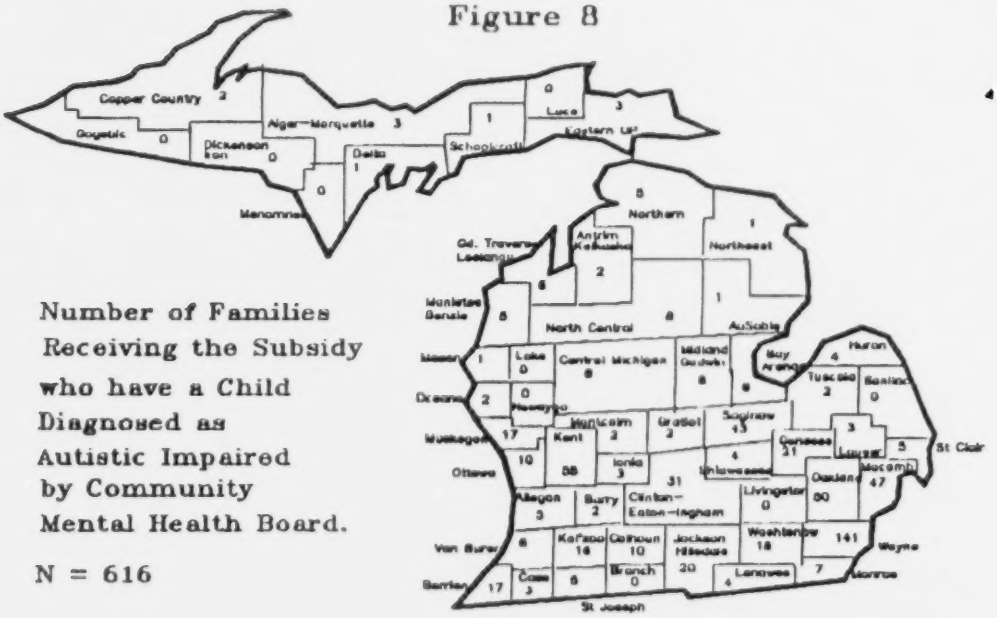
Figure 7



Number of Families Receiving the Subsidy who have a Child Diagnosed as Severely Multiply Impaired by Community Mental Health Board.

N = 1,779

Figure 8



Number of Families Receiving the Subsidy who have a Child Diagnosed as Autistic Impaired by Community Mental Health Board.

N = 616

Payments are Uniform for All Families

> *I thank all of the staff and workers who make things possible for my son. Thank God for the Family Support Subsidy Program.*
> *Saginaw County Parent*

Payments are uniform for all families and there are no provisions under the law for larger or smaller payments. During FY89 the monthly payment amount was $256.74.

The subsidy rates are patterned after the federal Supplemental Security Income (SSI) payments. The exact amount of the payment is determined annually after the federal government establishes its SSI payment rate, when the Michigan legislature sets the Subsidy appropriation.

Families are not eligible for payments after a child reaches age 18, because the child then becomes eligible, in almost all cases, for a payment under the federal SSI program.

The Subsidy Goes to Families in Every Part of the State

> *I am very grateful for the Family Subsidy Program because without it I know my other two children would have to give up or go without things they need or want so we could provide for my daughter the things she absolutely needs. My deepest thanks so all persons involved in making this program available to us.*
> *Central Michigan Parent*

Families in all parts of the state are receiving the subsidy. Figure 5 displays the distribution of families participating in the subsidy program by community mental health board catchment areas. Increases in enrollment occurred state-wide with the largest increases occurring in urban areas.

The distribution by community mental health board of families with a child identified as severely mentally impaired (SMI) is presented in Figure 6. A similar distribution for families with children identified as severely multiply impaired (SXI) and for families with children identified as autistic impaired (AI) are presented in Figures 7 and 8, respectively.

SUBSIDY FAMILIES REPORT

Families Have Flexibility in How They Use the Subsidy

I like the family support subsidy as it allows the parents to decide how to utilize the funds. This allows us to meet the unique needs of our child.
Genesee County Parent

The parent questionnaire contained a check list of 17 possible uses for the subsidy. Families were asked to check all ways in which they had used the subsidy in the last year. The percentages of all responding families who checked each use are presented in Table 2. Over half the responding families used the subsidy for clothing, education aides or toys, general household expenses, sitters for their child with handicaps, medical and health related expenses, and diapers. The uses are ranked from most to least frequent in Table 2. There was little change from the previous year in how the subsidy was used either in the percentage of families checking each use or in the ranking of the categories.

Families at different income levels report slightly different patterns of usage. Families at the lowest income level used the subsidy most often for clothing, general household expenses, education aides and toys, and transportation. Families at the highest income level also used the subsidy for clothing and education aides and toys. They were, however, less likely to use the subsidy for general household expenses or transportation and were more likely to use the subsidy for sitters and respite care, medical or health related expenses, and adaptive equipment for their child with handicaps.

The Subsidy has a Positive Impact on Families

I do appreciate that the State of Michigan has this subsidy....It helps change life for the whole family because of extra expenses like diapers, etc. and goes right down to helping all the family emotionally. Having a handicapped child who requires the care of SMI, SXI is very tiring emotionally and physically; like having a baby all your life but worse for getting care for them. It's a job 24 hours a day and, being human, parents and family wear down emotionally and physically. The subsidy helps.
Kent County Parent

The questionnaire asked families a series of questions regarding their perception of the impact of the subsidy on their family life; the helpfulness of the subsidy; and how much influence the subsidy had on their child remaining at home. Impact on family life was measured by five questions rated on a five point scale from very greatly (1) to not at all (5). The majority of families indicated that the subsidy had greatly improved their family life (Table 3).

Table 2
Categories of Use for the Subsidy

CATEGORY	PERCENT
Clothing	83.5%
Education Aides and Toys	63.2%
General Household Expenses	58.5%
Sitters for Child with Handicaps	54.7%
Medical Expenses and Health Related Needs	53.5%
Diapers	50.6%
Transportation Expenses	43.4%
Special Foods	38.6%
Adaptive Equipment for Child with Handicap	28.6%
Respite Care for Child with Handicaps	23.0%
Home Renovation Projects	14.6%
Care for Children without handicaps	11.1%
Camp	8.2%
Physical or Speech Therapy	7.2%
Counseling Services	4.5%
Nursing Respite Care	4.1%
Home Nursing Care	2.2%

N = 1257

Table 3
Impact of Subsidy on Families
Distribution of Responses

How much has the subsidy:	Very Greatly 1	Greatly 2	Some 3	A Little 4	Not At All 5
Improved your family's life overall	18.6%	32.9%	35.7%	9.4%	3.4%
Improved your ability to care for your child with handicaps	26.0%	36.3%	27.5%	7.0%	3.3%
Helped your family do more things together	25.5%	26.5%	30.0%	10.0%	8.1%
Eased your financial worries	28.4%	29.8%	26.8%	11.1%	3.9%
Reduced the stress in your family's life	21.9%	23.4%	35.5%	12.5%	6.7%

Table 4
Satisfaction with the Subsidy
Distribution of Responses

How satisfied are you:	Very Dissatis-fied 1	Dissatis-fied 2	Neutral 3	Satisfied 4	Very Satisfied 5
The amount of the subsidy	2.8%	5.4%	25.0%	51.4%	15.3%
Initial application procedure	2.3%	1.9%	9.8%	52.2%	33.9%
Yearly reapplication procedure	2.5%	2.6%	12.3%	49.3%	33.2%
CMH's handling of your application	2.3%	.8%	7.2%	46.6%	43.1%
Information you received about the program	2.9%	3.6%	9.9%	46.8%	36.7%

Table 5
Helpfulness of the Subsidy in Meeting Special Needs
Distribution of Responses

How helpful has the subsidy been to:	A Great Help 1	A Help 2	Somewhat of a Help 3	Very Little Help 4	No Help At All 5
Your family:	62.7%	25.7%	9.1%	1.7%	.7%
Your child with handicaps:	70.6%	22.2%	5.9%	.8%	.5%

Table 6
Influence on Decision to Have the Child Live at Home
Distribution of Responses

How much has the subsidy influenced your decision:	Not an Influence 1	A Small Influence 2	Somewhat of an Influence 3	An Influence 4	A Great Influence 5
To keep your child at home	60.5%	7.6%	6.9%	8.9%	16.1%
To return your child home	53.0%	14.9%	17.8%	7.9%	6.4%

Table 7
Adequacy of the Amount of the Subsidy
Distribution of Responses

How adequate is	More Than Enough 1	Enough 2	Just Enough 3	Not Quite Enough 4	Not Enough 5
the amount of the subsidy	3.7%	45.2%	28.0%	17.0%	6.1%

Two-thirds of the families were satisfied with the amount of the subsidy (Table 4). Families were asked how helpful the subsidy had been to them and to their child with handicaps. Five point scales scored from a great help (1) to no help at all (5) were used. Less than 3% of the families indicated that the subsidy had been very little to no help to them (Table 5). Less than 1% of families indicated that their child had not been helped. Families were also asked how much influence the subsidy had on their decision to keep or return their child with handicaps home. These questions were scored on five point scales from not an influence (1) to a great influence (5). Although families are reluctant to report that money has anything to do with their keeping their child at home, approximately 40% of the families indicated that the availability of the subsidy had some degree of influence in their decision to keep their child at home (Table 6). Of those families who had brought their child home, 41% indicated that the subsidy had influenced their decision. Comparison with prior years responses indicated no substantiated change in the level of satisfaction or impact of the subsidy on the families.

Families are Divided on Whether the Amount of the Subsidy is Enough to Meet Their Children's Special Costs

> *I like it. It has been a great help to us. We have used it to care for our child and promote the mental well being of our family. It is a program that works well. Please don't change it or cut it. The amount is fine.*
>
> *Washtenaw County Parent*

> *I think the program is excellent! But, as you know, medical bills (prescriptions), are always going up. Even plastic pants went up $1.20 in one year, just for one pair. Diapers went up $.80 in a year. Do you know how many diapers and plastic pants a 17 year old can go through in a year!!! So I think the monthly subsidy should be increased! Thank you.*
>
> *Macomb County Parent*

Families were asked two questions about the adequacy of the subsidy. One question asked how adequate the amount of the subsidy was in helping them to care for their child with handicaps (Table 7). This question was rated on a five point scale which ranged from more than enough (1) to not enough (5). Seventy-seven percent of families indicated that the amount of the subsidy was just enough to enough. However, only 67% of families were satisfied with the amount of the subsidy (Table 4). This indicates that the subsidy was seen as helpful but that a substantial number of families believed they needed more financial assistance in meeting the cost of caring for the special needs of their children.

Families Need Additional Respite Care and Life Planning Services

I'm very pleased with FSSP. It helps a lot, especially with extras. It would be nice if there was more funding for respite care, but even what we get helps immensely. Thank you.
North Central Michigan Parent

I'd also like to have more intense training for "life" for my daughter. Sometimes its hard for "mom" to know how to cope with her "differentness." We still love her dearly though and appreciate the help.
Newaygo County Parent

The family questionnaire asked families to indicate the level of need they had for 12 different services (Table 8). There were no major changes in the degree to which families indicated additional services were needed. Over 80% of families indicated a need for more respite care and sitters in addition to more help with life planning. Small increases in need were seen for all services except counseling which decreased slightly. These changes were small and most likely reflect changes in the group of families responding to the questionnaire rather than real changes in need.

Families are Satisfied with Non-Subsidy Services They are Receiving

All I can say is "THANKS" because it has helped us out a lot financially and look at things on a brighter side. Also with respite care which we don't use too much but when we have needed it, it has been provided.
Ottawa County Parent

Families were asked to rate their satisfaction with 12 services which they might be receiving (Table 9). Satisfaction was rated on a three point scale with 1 indicating they were satisfied and 3 indicating they were not satisfied. Satisfaction remained positive and similar to those found over the last three years.

Table 8
Families Need for Services
Distribution of Responses

My Family:	Needs More 1	Is Getting Enough 2	Does not Need 3
Respite Care	36.4%	28.8%	34.8%
Sitters	45.2%	34.1%	20.7%
Counseling	16.9%	28.6%	54.4%
Parent Support Groups	20.2%	41.0%	38.8%
Training on Child's Physical Needs	15.4%	38.6%	46.0%
Speech or Physical Therapy	30.6%	48.6%	20.8%
Medical Consultation	14.9%	60.3%	24.8%
Psychological or Educational Assessment	11.1%	63.8%	25.1%
Training on Child's Behavior Problems	25.4%	31.4%	43.2%
Life Planning	41.8%	31.6%	26.5%
Training to Teach Child Skills	30.4%	47.0%	22.5%
Help with Household Chores or Care of Child	26.6%	34.2%	39.1%

Table 9
Families Satisfaction with Non-Subsidy Services
Distribution of Responses

This Service is:	Satisfactory	Could be Better	Unsatisfactory	Not Used	Not Available
Respite Care	29.1%	13.3%	4.6%	46.5%	6.4%
Sitters	29.1%	18.7%	4.7%	36.1%	11.5%
Counseling	23.0%	7.7%	1.9%	61.7%	5.8%
Parent Support Groups	32.3%	9.2%	2.2%	49.2%	7.2%
Training on Child's Physical Sersats	31.0%	10.2%	2.5%	49.8%	6.5%
Speech or Physical Therapy	46.3%	18.2%	4.6%	26.1%	4.8%
Medical Consultation	49.0%	11.5%	2.9%	32.1%	4.5%
Psychological or Educational Assessment	55.8%	10.3%	2.6%	28.2%	3.1%
Training on Child's Behavior Problems	27.0%	13.5%	3.9%	49.0%	6.6%
Life Planning	23.4%	17.5%	5.5%	42.5%	11.1%
Training to Teach Child Skills	40.8%	17.1%	4.2%	32.5%	5.4%
Help with Household Chores or Care of Child	18.5%	11.1%	4.0%	54.9%	11.5%

ENCOURAGING FAMILIES TO PARTICIPATE

465 of the 652 New Subsidy Applicants were Identified by the Community Mental Health Boards' Outreach Activities

> *I think the Subsidy is wonderful. It's changed my family's life a whole lot: mentally, physically, and financially. Thank you very much.*
> *Detroit-Wayne County Parent*

Boards report that 465 new subsidy applicants were identified as a result of their outreach activities during FY89. The outreach activities reported are varied and extensive. Most Boards view the local school or intermediate school district as the primary target for their outreach. In addition, many Boards contacted, met with, and provided brochures to neo-natal unit staff, clinics, doctor's offices, and parent groups, among others.

The Subsidy is Part of a Continuum of CMH Family Support Services Which Also Includes Respite Care; Family Counseling and Training; Case Management; Parent Support Groups; and More

> *We like the availability of sitters and respite care. The people that work for family support have been very good and are always willing to help when you need something.*
> *Sanilac County Parent*

Outreach to families who would be eligible for the subsidy if their children were returned home from an out-of-home placement is generally initiated by the Boards' Family Support Programs. The Family Support Programs, at most Boards, coordinate the Subsidy program for the county and determine family eligibility. The type of outreach depends upon the family situation.

In addition to the Subsidy, the Boards' Family Support Programs also offer the services needed by the families of children with severe disabilities in order to remain intact. Services include respite care, sitters, family counseling and training. Also included are permanency planning, life planning, case management, in-home services (some paid by Medicaid via a waiver), parent support groups, and others.

Before the Subsidy and family support services were available, families had been encouraged to permanently give up their children with developmental disabilities for the "good of their children."

CMH Family Support Services Utilize Permanency Planning Principles

Children need to have permanent family relationships in order to live and thrive. The Department of Mental Health's policy is to assure that children with developmental disabilities are not deprived of their needed permanent family relationships. Permanency Planning Consultants are available to help the practice change to match the policy. Casework practice, policy and funding priorities had often made it easier to place a child out-of-home than to devote services and resources to keeping families together. Permanency Planning has facilitated the redesign of the admission process from long-term placement expectations to one which encourages the child's returning home as soon as possible.

Even children with overwhelming medical needs and technical dependency are going home to live with their families. Others for whom this is not possible are in transitional foster care or are being adopted.

CMH Family Support Services are Utilizing Michigan's Childrens' Medicaid Waiver for 100 Children with Severe Medical Disabilities

In addition, the Medicaid Children's Model Waiver II Program has been initiated on a statewide basis. Under the federal regulation governing this waiver, children with severe developmental disabilities who also have severe medical problems can receive an expanded range of services at home. These children, most dependent upon machines, are receiving care at home rather than institutionalization in a regional center.

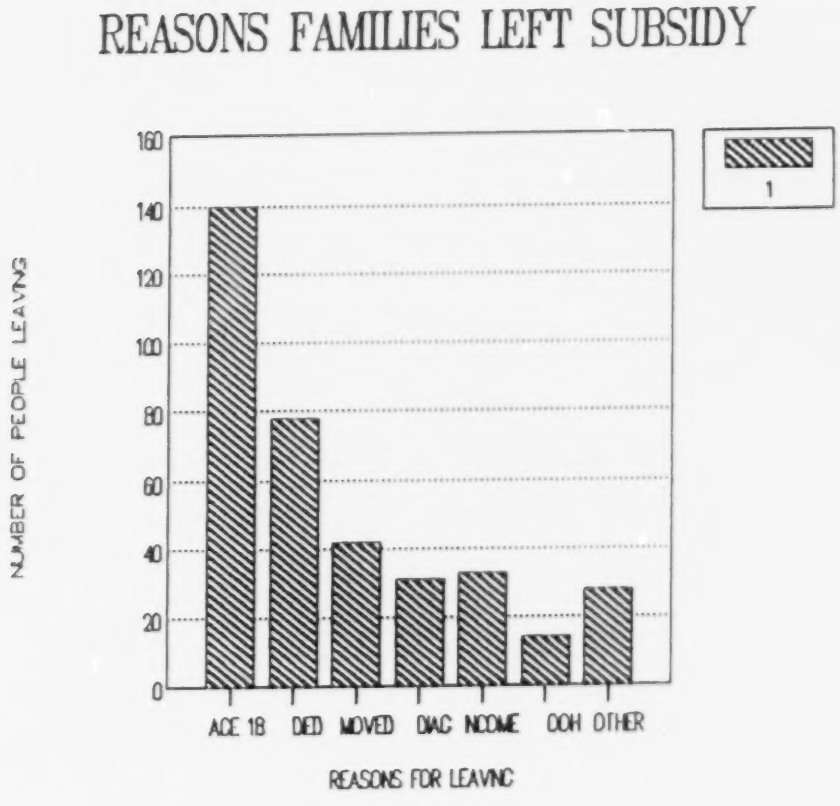
Family Support Services, which include the Family Support Subsidy, Permanency Planning, and the Medicaid Waiver, give families the network of supportive services that makes it possible for children with developmental disabilities to remain in and return to birth or adoptive homes. In addition to supporting families, these services save other state and federal resources by delaying or preventing out-of-home placement.

A Total of 366 Families Left the Subsidy Program During FY89; 140 Because the Child Became an Adult at 18 Years Old

The reasons the 366 families left the Subsidy during FY89: (Fig. 9)

140 - Children turned 18
78 - Children died
42 - Families moved out of Michigan
31 - Children had a change in diagnostic category which made them ineligible for the Subsidy
33 - Families' incomes went above the allowed amount
14 - Children were placed out-of-home
28 - Other reasons (12 families did not renew, 5 children went to adult placements, 7 children we do not know about because they are not clients of Mental Health and we do not have the right to intrude further, and 4 were erroneously reported.)

366 TOTAL



ANNUAL EVALUATION

The Subsidy Program is Evaluated Every Year Using Information Collected From Four Sources

Each year, the Subsidy Office gathers information from four sources in order to satisfy the reporting requirements of the Subsidy Act: 1) Community Mental Health annual reports on the Subsidy, 2) follow-up reports on children leaving the subsidy program, 3) the questionnaire requested from parents annually, and 4) the data base derived from the applications of families receiving the Subsidy.

1) Community Mental Health has the responsibility for intake and helping the parents through the process of application and annual renewal. The Subsidy's FY89 Community Mental Health Annual Report survey asked for information about general family support services, CMH out-of-home placements and questions about the workings of the Subsidy Program. Of the 55 CMH Boards, 53 reported.

2) All 55 boards submitted detailed follow-up information about each family who was removed from the Subsidy Program because their child was placed out-of-home.

3) Parent questionnaires are sent to each family in the month of the family member's birthday during their re-application procedure. The FY89 questionnaire asked about use of the subsidy, satisfaction with the subsidy program, adequacy of the subsidy, other services the family needed, and the family's satisfaction with non-subsidy services they were receiving. The questionnaire was anonymous and optional. Of the 3,491 families enrolled in the Subsidy Program, 1,257 or 36% returned the voluntary questionnaire. This represents a decrease of 2.8% in the response rate to the questionnaire from the previous year.

Subsidy Families Represent a Wide Range of Income Levels and Different Race/Ethnic Backgrounds

Families responding to the questionnaire were representative of all families in the subsidy program with two exceptions. Families who responded to the questionnaire had children with handicaps approximately 1.5 years older, on average, than all families enrolled. The second exception is that black families were less likely to return the questionnaire than were non-black families. Table 10 presents the demographic characteristics for the sample of families responding to the questionnaire and for all families in the program. As in the previous year, over 80% of the families responding to the survey had been in the program longer than ten months.

Table 10
Characteristics of Families Receiving the Subsidy

Characteristic	Survey Sample Percent	All Recipients Percent
Age of Child in years		
3 or younger	24.7	14.4
4 to 6	20.7	20.2
7 to 11	31.6	33.3
12 to 17	18.5	32.1
Not reported	4.7	
Mean	7.1	8.9
Standard deviation	4.4	4.6
Gender		
Male	58.9	56.3
Female	40.1	40.4
Not reported	1.0	3.2
Race/Ethnic Group		
Native American	0.3	0.4
Asian/Pacific Islander	1.0	0.8
Black	12.6	20.0
Hispanic	2.8	2.4
White	79.5	68.1
Not reported	3.8	8.3
Diagnostic Group		
Severely mentally impaired	32.1	31.4
Severely multiply impaired	49.2	51.0
Autistic impaired	17.6	17.6
Not reported	1.2	
Taxable Income Level		
$45,000 to $60,000	14.9	11.8
$20,000 to $44,999	39.4	37.8
Below $20,000	41.4	50.4
Not reported	4.4	

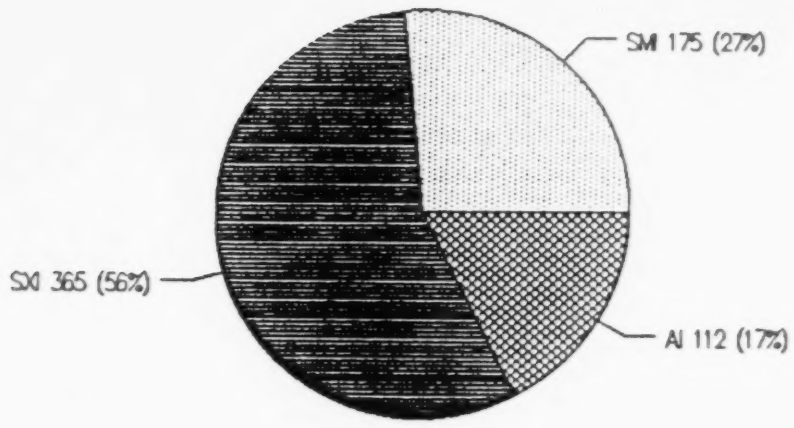
The Subsidy has Fostered Increased Cooperation Among Community Mental Health Boards and Intermediate and Local School Districts

The Family Support Subsidy has initiated increased cooperation between CMH Boards and Intermediate and local School Districts. The increased cooperation has proven to be helpful to families
seeking services for their children with severe disabilities.

It is Sometimes Difficult for the Schools to Diagnose an Infant or Very Young Child

One difficulty in using the school diagnosis as a threshold requirement for the Subsidy is the difficulty in determining the diagnosis of an infant or a very young child. Many times it is difficult to determine the level of severity of a child's mental impairment until the child gets older. Because of this, the schools have a pre-primary diagnostic category which qualifies infants and young children for special education services without requiring a specific diagnosis. A specific diagnosis is required, however, for eligibility for the Subsidy. School multi-disciplinary evaluation teams (METs) are reluctant to make a specific diagnosis that is not required for special education services especially since it might change as the child develops. Advocacy groups, schools, and CMH Boards are working together to solve this difficulty in individual instances.

NEW APPLICATIONS BY DIAGNOSTIC CATEGORY 1989



RECOMMENDATIONS TO THE PROGRAM AND TO THE LEGISLATURE

The Three Main Programmatic and Legislative Recommendations for change are:

1) Raise the Subsidy Amount to the Current SSI Rate as Stated in the Subsidy Act.

2) Raise the 1983 Cap on Income Eligibility by a Cost of Living Factor to Bring it in Line with 1991 Inflation Rates.

3) Expand the subsidy program to families with children who have severe physical health or emotional impairments.

In addition to the fact that the Subsidy achieves the purpose for which it was enacted, families and advocates unanimously agree that the program works well. Families advocate that the program continue and that it keep up with inflation. Families are concerned to see that rising costs outstrip increases in the Subsidy rate. We recommend that the Subsidy keep abreast of the current SSI rate at all times.

Also, the Subsidy was enacted with a maximum taxable income eligibility cap of 60 thousand dollars. During the six years since enactment of the Subsidy, spending power has eroded. We recommend that the Legislature consider removing the cap or raising it.

Finally, there continue to be recommendations to expand the Subsidy to other families of equally needy children with severe medical disabilities or severe emotional impairments. Most mentioned are the special education diagnostic categories of Physical or Otherwise Health Impaired (POHI) and Emotionally Impaired (EI). We recommend that the Legislature consider other populations for whom the Subsidy would prove effective.